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Invited Editorial

EXTREQOL identifies ongoing challenges in maximising quality of survival in men with mCRPC

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The last decade has seen many new developments and improved therapies for men with metastatic castrate resistant prostate cancer (mCRPC), but the exact sequencing of these therapies for any individual man remains uncertain. This is partly due to the heterogeneity of prostate cancer and tumour factors such as Gleason Grade, PSA kinetics, and the sites of recurrence (visceral, bone or nodal) that will influence the sequence in which these drugs are prescribed. Currently there is a lack of sufficiently robust biomarkers that predict response or toxicity/tolerability of any individual treatment. Patient co-morbidities, potential toxicities of drugs, and importantly patient choice depending on their individual circumstances, will also have an impact [1].

The management of mCRPC requires a multidisciplinary team (MDT) approach, with the patient receiving information from different specialties. It is therefore important that MDT members are aware of each other's roles and can provide patients with accurate and consistent information to guide treatment decisions. The American Society of Clinical Oncology (ASCO) guidelines for survivors of prostate cancer recommend that an individual's information needs at all stages of disease are assessed and patients provided with or referred to the appropriate sources for information and support [2]. However, a series of studies from Canada with men with advanced prostate cancer (the majority of whom were castrate resistant), their partners, and health professionals identified three areas that needed attention [3-5]. These were (a) treatments and associated side effects, (b) progression of the disease and (c) available supportive care services.

As part of an ongoing prospective study examining the EXperiences, TREatments and Quality Of Life (EXTREQOL) in men diagnosed with mCRPC, we conducted an initial survey between September 2016 and February 2017, exploring the views of 109 UK Health Care Professionals (HCPs) about the treatment and clinical management of mCRPC at their hospitals. 60% of respondents were clinicians affiliated to the British Uro-oncology Group (BUG) and 11% nurses from the British Association of Urology Nurses (BAUN). Topic areas covered different areas of clinical practice including information provision, decision making, treatments, pain relief and follow up. The findings highlighted the challenges to providing holistic care for this group of men within busy NHS clinics and gaps and inconsistencies in the provision of information and use of terminology.

We know that men with mCRPC report a significantly poorer Quality of Life (QoL) and increased pain compared with other groups of prostate cancer patients [6], so consultations are likely to take more time, involve pain management and /or supportive care referrals. It was apparent that many of the new and follow up clinics were understaffed and extremely busy. A common finding was the presence of one clinical oncologist (53%) and a research (48%) or oncology nurse (40%). The absence in clinic of palliative care physicians (93%), medical oncologists (67%), urologists (65%) and specialist urology nurses (73%) was notable especially as 43% nominated pain as the most troubling symptom for patients at presentation. A combination of too few staff and resources is detrimental to the well-being of both

patients and HCPs in whom it can lead to increased stress and burnout [7, 8]. Part of the problem was that many respondents had to manage these patients in general urological oncology clinics, alongside others with a variety of different stages of prostate cancer and other urological tumours. Having dedicated clinics would enable clinicians with a specific interest in this stage of the disease to focus appropriately on the perhaps more complex needs of this group of patients and allow added input from the palliative care team. There was an appeal from clinicians for more specialist nurse support, which needs to double to match that provided for breast cancer patients [9].

The majority of clinicians were able to offer enzalutamide, abiraterone and docetaxel as treatment options but others were not routinely available, including radium-223 (13%), cabazitaxel (14%), mitoxantrone (35%) and denosumab (71%). We acknowledge that single time-point survey data are sensitive to policy changes, however, despite evidence that some of these agents may be effective before or after chemotherapy, there were restrictions placed on the sequencing of treatments in certain geographical locations. As the primary therapeutic aims in mCRPC treatments are not only to increase overall survival, and delay progression but also to palliate symptoms and improve quality of life, it was disappointing to see how infrequently Patient Reported Outcome (PRO) data were collected outside of a trial setting (4%). Though advocated, routine PRO use has yet to become the norm [10], yet there is growing evidence to show it benefits patients, including increasing survival in patients with metastatic cancer [11].

Providing the patient agreed, most HCPs always allowed family and friends to be present at treatment consultations (85%). 59% said they gave patients as long as they needed in order to make a treatment decision, but this was influenced to some extent by whether or not patients lived alone. Key questions concerning prognosis and how treatments work are best answered by the treating clinician [12]. Important as this is, differences emerged between what clinicians and nurse specialists believed was covered during the mCRPC diagnostic consultation. Our results showed that few always discussed prognosis (26%), side effect amelioration (50%), patients' current goals (38%), and supportive care (24%). Additionally, only 37% reported always checking explicitly that patients understood the purpose of their treatment. Discussions around these issues can be distressing for both patients and family members making some of them avoidant of the subject despite paradoxically needing this information to help with treatment decision making.

Few clinicians (53%) felt confident in being able to ameliorate the side effect of fatigue compared to a majority of nurses (71%). Yet fatigue is a key symptom in this group of patients, especially those who have received long term androgen deprivation therapy, which can lead to reduced bone mineral density, muscle mass/strength and physical functioning [13, 14]. Exercise regimes can improve QoL, fatigue, fitness and function for men with prostate cancer, but for those who have mCRPC with bone metastases the outcome may be different. We await with interest the results from a US study of men with mCRPC randomised to 12 months of

psychosocial support +/- high intensity aerobic and resistance training, followed by self-managed exercise and behavioural support for an additional 12 months [15].

HCPs supplemented their own information giving with that contained in National Cancer Charity pamphlets or Prostate Cancer Charity leaflets that have links to their related websites. Our results showed the majority (85%) said they gave patients website information, most often Macmillan (54%) and Prostate Cancer UK (51%). Many websites use the term mCRPC though HCPs rarely said they did so with their patients (19%); most (56%) preferring the phrase advanced prostate cancer (APC). The term 'castration resistant', whilst a correct description, has punitive associations not welcomed by most patients; Pezaro and colleagues [16] suggest it is time to acknowledge that the label may be alienating, recommending the prostate cancer community describe it as metastatic or APC.

This survey revealed the status quo is to manage men with mCRPC in general urological oncology clinics which has some clear implications. Staffing levels/mix were not conducive to enabling healthcare professionals to be able to focus on the often more complex needs of this population and it was evident important topics, such as prognosis and amelioration of side-effects, were not routinely discussed in the diagnostic consultation. These circumstances make achieving optimal quality of life for patients much more challenging. Solutions may lie in dedicated clinics, better access to specialist nurses, even a mCRPC nurse role and earlier links to the palliative team to draw on their services for the best possible symptom control.

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References

1. Ryan CJ, Smith MR, Fizazi K, Saad F, Mulders PFA, Sternberg C et al. Abiraterone acetate plus prednisone versus placebo plus prednisone in chemotherapy-naïve men with metastatic castration-resistant prostate cancer (COU-AA-302): final overall survival analysis of a randomised, double-blind, placebo-controlled phase 3 study. *Lancet Oncol*. 2015; 16(2):152-60
2. Resnick MJ, Lacchetti C, Bergman J, Hauke RJ, Hoffman KE, Kungel TM. Prostate Cancer Survivorship Care Guideline: American Society of Clinical Oncology Clinical Practice Guideline Endorsement. *Journal of Clinical Oncology* 2015, 33:1078-1085.
3. Carter N, Bryant-Lukosius D, DiCenso A, et al. The supportive care needs of family members of men with advanced prostate cancer. *Can Oncol Nurs J* 2010 20:166–176
4. Carter N, Bryant-Lukosius D, DiCenso A, et al. The supportive care needs of men with advanced prostate cancer. *Oncol Nurs Forum* 2011 38:189–198

5. Carter N, Miller PA, Murphy BR, et al Healthcare providers' perspectives of the supportive care needs of men with advanced prostate cancer. *Oncol Nurs Forum* 2014 41:421–430
6. Bryant-Lukosius D, Browne G, DiCenso A, Whelan T, Gafni A, Neville A, Sathya J. Evaluating health-related quality of life and priority health problems in patients with prostate cancer: a strategy for defining the role of the advanced practice nurse. *Canadian Oncology Nursing Journal/Revue* 2010; 20(1):5-14.
7. Fallowfield L, Guarneri V, Akif Ozturk M, May S, Jenkins V. Blurring the boundaries in the doctor-patient relationship. *Lancet oncology* 2014; 15: 1423-24
8. Bloomfield D, Fallowfield L, May S, Jenkins V. Too hot, too cold or can we get it just right? What emotional distance should oncologists keep from their patients? *Clinical Oncology*, 2017, 29 (4): 205–206.
9. Prostate cancer patients' discriminated against.
<http://www.telegraph.co.uk/news/health/news/11130248/Prostate-cancer-patients-discriminated-against-charity.html> accessed Nov 23rd 2017
10. Synder CF & Aaronson NK. Use of patient-reported outcomes in clinical practice. *The Lancet* 2009; 374:369-370
11. Basch E, Deal AM, Kris MG, Scher HI, Hudis CA et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *Journal of Clinical Oncology* 2016; 34 (6): 557-565.
12. Warren E, Footman K, Tinelli M, McKee M, Knai C. Do cancer-specific websites meet patient's information needs? *Patient education and counseling*. 2014 Apr 30; 95(1):126-36.
13. Galvão DA, Newton RU, Gardiner RA, Girgis A, Lepore SJ, Stiller A, Mihalopolous C, Occhipinti S, Chambers SK. Compliance to exercise-oncology guidelines in prostate cancer survivors and associations with psychological distress, unmet supportive care needs, and quality of life. *Psycho-Oncology*. 2015 Oct 1; 24(10):1241-9.
14. Wall BA, GALVÃO DA, Fatehee N, Taaffe DR, Spry N, Joseph D, Hebert JJ, Newton RU. Exercise Improves V̇O₂max and Body Composition in Androgen Deprivation Therapy-treated Prostate Cancer Patients. *Medicine and science in sports and exercise*. 2017 Aug; 49(8):1503.
15. Saad F, Kenfield SA, Chan JM, Hart NH, Courneya KS, Catto J, Finn SP, Greenwood R, Hughes DC, Mucci LA, Plymate SR. Intense exercise for survival among men with metastatic castrate-resistant prostate cancer (INTERVAL–MCRPC): A Movember funded multicenter, randomized, controlled phase III study. *Pezaro CJ, Omlin A, Mastris K et al. Precision, complexity and stigma in advanced prostate cancer terminology: it is time to move away from “castration-resistant” prostate cancer. Annals of Oncology* 2017; 28 (8):1692-1693

16. Pezaro CJ, Omlin A, Mastris K et al. Precision, complexity and stigma in advanced prostate cancer terminology: it is time to move away from “castration-resistant” prostate cancer. *Annals of Oncology* 2017; 28 (8):1692-1693